

**HIV/AIDS RELATED STIGMA AND DISCRIMINATION IN THE BUKAVU
COMMUNITY, DEMOCRATIC REPUBLIC OF THE CONGO**

Barthélémy Wenga Mulindwa

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Africa Centre for HIV/AIDS Management
Faculty of Economic and Management Sciences
Study leader: Dr. Thozamile Qubuda
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DECLARATION

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DEDICATION

This thesis is dedicated to:

My parents: Mulindwa and Mukeina

Sisters: Odile, Brigitte, Odette and Mama Liki.

Brothers: Denis, Bonnit and Ghamma

My precious daughter, Elizabeth K. Mulindwa.

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SUMMARY

The objectives of this study were to identify stigmatization problems in Bukavu community and what support services are available, to establish how often these services are available and to identify the factors that hinder the community from using these services.

The data obtained from Bukavu community has been collected by using a questionnaire containing quantitative questions. Qualitative questions were used precisely for different organizations which are working in HIV/AIDS field in order to gather information about HIV/AIDS services provided into the community.

A sample size of 150 people was selected from different area. Four HIV/AIDS organizations have been selected for interview. One person was chosen for interview according to his/her manager position. The age categorizations of the subjects started from 15 and above.

Generally the respondents indicated a good feeling and behaviors to PLWHA. Furthermore, the result has indicated that health care worker, counselors, did not respect the principle of the confidentiality. 59% of respondents agreed that PLWHA should tell others that they are HIV positive in order to protect those who are not infected. Qualitatively, the results showed the support services provided by the HIV/AIDS organization were limited in the community.

OPSOMMING

Die doelwitte van hierdie studie was om stigmatiseringsprobleme in Bukavu gemeenskap te identifiseer en om te bepaal watter ondersteuningsdienste beskikbaar is, om vas te stel hoe dikwels hierdie dienste beskikbaar is, en die faktore wat die gemeenskap van die gebruik van hierdie dienste verhinder te identifiseer.

Die data wat verkry is uit Bukavu gemeenskap is versamel deur gebruik te maak van 'n vraelys met kwantitatiewe vrae. Kwalitatiewe vrae is juis gebruik vir verskillende organisasies wat werk in die MIV/VIGS-veld om inligting oor MIV/VIGS-dienste wat gelewer word in die gemeenskap in te samel.

'n Steekproefgrootte van 150 mense is gekies uit verskillende areas. Vier MIV/VIGS-organisasies is gekies vir 'n onderhoud. Een persoon is gekies vir 'n onderhoud op grond van sy/haar bestuursposisie. Die ouderdom kategorië van die deelnemers het by 15 begin.

Die respondente het oor die algemeen 'n goeie gevoel en gedrag getoon teenoor mense wie leef met MIV/VIGS. Verder het die resultate aangedui dat gesondheidswerkers en beraders nie respek het vir die beginsel van die vertroulikheid nie. 59% van die respondente het saamgestem dat mense wie leef met MIV/VIGS ander moet vertel dat hulle MIV-positief is om diegene wat nie geïnfecteer is nie te beskerm. Die resultate het getoon dat die dienste wat gelewer word deur die MIV/VIGS-organisasie word beperk is in die gemeenskap.

LIST OF ACRONYMS

AIDS	Acquired immunodeficiency syndrome
ASF	Associations de Santé Familiale
HIV	Human Immunodeficiency Virus
NGO	Non- Governmental Organisation
PLWHA	People Living with HIV/AIDS
PNLS	Programme National de Lutte Contre le Sida
PNMLS	Programme National
UCOP	Union Congolaise des personnes Vivant avec le VIH/SIDA
UNAIDS	The Joint United Nations Programme on HIV/AIDS
USAID	United States Agency for International Development

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CHAPTER 1: INTRODUCTION

1.1. Introduction

Sub-Saharan Africa is more heavily affected by HIV and AIDS than any other region of the world. An estimated 22.5 million of people are living HIV in the region-around two thirds of the global total. In 2009 around 1.3 million people died from AIDS in sub-Saharan Africa and 1.8 million people become infected with HIV. Since the beginning of the epidemic, 14.8 million children have lost one or both parents to HIV/AIDS (UNAIDS, 2010).

In Democratic Republic of the Congo, the first description of HIV infection has been defined to a particular population group such as: homosexuals, commercial sex workers, drug users, children born by infected parents. Because of this categorization, if someone find himself not include in that group means he/she is not concerned by the plague. In DRC some people argued that AIDS was an imagination disease in order to discourage lovers in sexual intercourse. Some Cameroonians claimed that it was a ploy to discourage sexual activity (Tangwa B.Godfrey, 2001). AIDS could therefore be perceived by some people as a divine punishment due to the misbehaviour.

According to Kaldjian et al., (1998) and Ayranci, (2005) said: in Ghana and many countries of Sub-Saharan Africa, HIV transmission occurs primarily through heterosexual intercourse. In these countries, HIV/AIDS is widely viewed as a consequence of sexual immorality or immoral behaviours, thus, infected individuals are considered responsible for acquiring the disease. In some cases, the infection is perceived as a punishment given by God to perpetrators of sins like prostitutions, promiscuity, drug use or homosexuality.

After a period of time, AIDS became a shameful disease which still connected to stigma and discrimination into the different communities. HIV/AIDs related stigma and discrimination have been linked to

misconceptions about the disease, fear of the disease due to its manifestations and fatality, and to the association of HIV/AIDs with stigmatized/marginalized individuals in the community (Herek and Glunt, 1988; Alonzo and Reynolds, 1995; Boer and Emons, 2004).

Discrimination has often been rampant. Ostracism, isolation and rejection have been common place in the lives of people identified to have AIDS (Carr and Gramling, 2004). HIV/AIDS- related stigma can range from a simple gossip to outright discrimination, resulting in job loss, house evictions, rejection, isolation and even killing of an HIV infected person. It can stem from legislative, employment policies, hospital policies, cultural beliefs, or individual behaviours, thoughts and attitudes (Standing, 1992; Zwi, 1993; Aggleton, 1996).

Regardless of the evolution of HIV/AIDS pandemic, affecting all races, all social classes without preference and the evolution of mentalities, AIDS still maintains a negative connotation within African communities.

1.2. HIV/AIDS in Democratic Republic of the Congo

The Democratic Republic of the Congo (DRC) was one of the first sub-Saharan African countries to recognize HIV/AIDS when its first cases were registered in 1983. The joint United Nations program on HIV/AIDS (UNAIDS) estimated there were between 400,000 and 500,000 people living with HIV/AIDS (PLWHA) and 1.3 percent prevalence among adults at the end of 2007; recent studies suggest prevalence may increase. Despite an abundance of natural resources, the DRC remains mired in poverty. Health indicators are among the worst in the world and reflect the hardships resulting from the protracted conflict and the corresponding deterioration of health services throughout the country. Consequently, the health sector's ability to respond to the needs of the citizens of the DRC has declined significantly over the past decades. It is estimated 70 percent of the population has little or no access to health care, including HIV/AIDS services (USAIDS, 2010).

According to the PNLS DRC (2008) antenatal care surveillance survey data, the mean prevalence among pregnant women is 4.3%. The data obtained from the centres providing services for the prevention of HIV transmission from mother to child the rate is 1.6% to 1.9% respectively in 2008 and 2009. Recently UNAIDS (2008) estimated HIV prevalence among women who have suffered sexual violence in areas of armed conflict to be as high as 25.6%, compared with the 1.8% prevalence among women in the general population. This is primarily attributable to the use of sexual violence as a weapon of war. In parts of the DRC, the prevalence of rape is believed to be the highest in the world.

HIV prevalence is estimated at 7.6% among women displaced by war and 7.8% among military women (Kim AA 2008-2009). Prevalence of HIV among the youth aged from 15 to 24 was estimated around 4%. The survey of sero surveillance among pregnant women was estimated at 3.9%. Survey suggests the epidemic may be changing, with rural rates surpassing urban rates in some area for the first time. While previous data showed a higher prevalence in urban areas, the 2008 ANC Surveillance data found HIV prevalence in rural areas was 4.6%, compared to 3.7% in the capital, Kinshasa, and 4.2% in other urban areas (PNLS, 2008). According to statistics of VCT centre of PNLS (2010), the main mode of HIV transmission is heterosexual sex, which accounts for 83% of new cases.

In view of the prevalence rate of HIV in the Democratic Republic of the Congo, several factors contribute to HIV infection. Among these factors, the most important are: Limited access to prevention services, promiscuity, multiple sexual partners and mobility of the population, country's political situation (wars), socio cultural barriers, poverty, rapes, Irregular payment especially for government workers, low salary, and unemployment.

1.3. Bukavu as a study area

Bukavu is the city of the Democratic Republic of the Congo located on the southwest of Lake Kivu. Bukavu is the city of south Kivu province. It has a

population of over 245.000 people. The city is close to the Republic of Rwanda separated by Lake Kivu and the Ruzizi River.

Bukavu has been affected by Numerous Problems: crime, rape, looting, and massacre have been committed in 1996 and 2004 during the rebellions where many troops were involved such as: Rwandan troops, Ugandan, Burundian, the troops of Laurent Nkunda, Mutebusi, the Congolese army, FDLR (Force démocratiques pour la liberation du Rwanda) and the Mai- Mai militia (local defence force). The people are often more concerned about their safety situation than HIV/AIDS.

The majority of the population is Christian. The study area was chosen for the research due to its easy access to me, and it is a place I was born and grew up. I experienced some men abandoned by their spouses due to rumours/gossips related to HIV/AIDs status. HIV positive person from Bukavu community are served by Panzi hospital because they are few actors in Bukavu responding to the need of treatment for people living with HIV/AIDS. It is necessary for the researcher to apprehend the community's feelings and behaviours face to people living with HIV/AIDS in order to help the patients from this community.

1.4. The context in Bukavu

Through the estimation made by PNMLS (National Multi –sectorial fight against AIDS in 2011) reported the last survey revealed the rate of HIV/AIDS in the city of Bukavu decrease from 4% to 1.6%.

It should be noted that in the future the rate of pandemic will increase due different factors such as: serious poverty of the population, unemployment, movements of troops and the population, war in rural areas, lack of adequate sanitation, lower levels of knowledge and awareness about HIV, illiteracy, social status that African has given to the woman, sexual violence that are used as a weapon of war by most forces involved in the conflict. According to UNAIDS (2005) statistics estimated that 60% of the

combatants involved in the war in DRC are HIV positive. In eastern DRC, it is estimated that three out of four women have been raped during the fourteen years of the better conflict (Ruth K., and Judy W., 2009).

Recently in February 2009 the church service was raided and the pastor's wife raped before the congregation, on the night of 30, April 2009, a man was tied to a chair and watched as five armed men repeated by rape his wife and latter abduct his two daughter (Ruth K., and Judy W., 2009). In the same thought, Holt (2004) said: A recent scandal in the Democratic Republic of the Congo has revealed that girls, as young as 10 years old, are not immune to rape by even United Nations soldiers supposedly posted at the camps to protect them from marauding rebels.

It is can be deduced that, the risk of HIV infection as a result of assault or rape is higher than it is from normal consensual sexual intercourse. This is because forced intercourse is violent and can cause the tissues of the vagina or anus to tear and bleed. With gang rape the risk is even higher because more than one rapist is involved (Jenny Page et al.2004).

On the other hand, poverty of people leads to what might be called "survival sexuality", proliferation of places where beers and other alcoholic beverages are sold with three or four rooms reserved for sexual need. In conclusion, people in marginalized communities are less likely to have access to health care, and thus more likely to suffer from untreated STIs, which increased the probability of HIV transmission.

1.5. Problem statement

In the unstable eastern Democratic Republic of the Congo (DRC), where people are often more concerned about their safety than HIV/AIDS, extensive stigma and discrimination are driving the epidemic underground, especially in the province of South Kivu.

When someone is told that their brother has HIV, their response is often of fear and the desire to give up that person to be cared for by an organization. They seem to want nothing to do with an infected person or they often lie about the illness to avoid community rumours/gossips which will lead to discrimination. A lot of people who know they are infected do not own up to their HIV-positive status because they fear discrimination. They argue, maybe my wife will leave me, my children will be avoided by the neighbour's children, who will no longer want to play with them, fearing they will get infected, or the property-owner will throw them out.

The researcher witnessed some men have been abandoned by the partners due to rumours/gossips related to HIV/AIDs status of her husband suspected to be in love with women supposed died with illness related to AIDS . In Bukavu community disclosing of HIV status of a person to uninfected partner, most often leads to the dissolution of the marriage as well as for the couple engaging for the future marriage. Some infected people accusing other kind of sickness like diabetes while they suffer from AIDS.

A qualitative research conducted by Daftary et al. (2007) indicated HIV positive individuals prefer to tell others that they have tuberculosis rather than deal with the stigma of being HIV positive. That is the reason why many people are afraid to contact a doctor, counsellors, NGOs which could be able to help by provide different services such as : being tested, ARVs, counselling and education services... Something needs close attention; HIV/AIDs stigma and discrimination, limited of VCT centres constitute a main obstacle for HIV prevention. Ruth K. and Judy W. (2009) argued: Bukavu also has limited VCT centres and stigma associated with infected persons is over whelming.

1.6. Research question

To what extent does HIV/AIDS related stigma and discrimination hinder the accessibility to services in the Bukavu community?

1.7. Aim and objectives

The purpose of this study is to identify factors that contribute to the stigma about and discrimination against people with HIV/AIDS in the Bukavu community, Democratic Republic of the Congo. The study aims to build awareness of how important it is to provide services related to HIV/AIDS in the community.

It also aims to encourage other researchers to join those who want to tackle stigma and discrimination, which are some of the main barriers to the prevention of HIV/AIDS in communities.

1.8. Specific objectives

- To identify stigmatization problems in Bukavu community
- What support services are available in Bukavu community
- To establish how often services are available
- To identify what hinder community from using services.
- Determine the feelings and behaviors of Bukavu community people

CHAPTER 2: REVIEW OF RELATED LITERATURE

This chapter announces the previous researches which have been done on HIV/AIDS related stigma and discrimination. The literature review first focus on definition of key concepts and the impact of HIV/AIDS related stigma and discrimination.

The importance of a literature review, said by Christensen: “Will tell you whether the problem you have identified has already been researched. If it has, you should either revise the problem in light of the experimental results or look for another problem, unless there is a good reason to replicate the study” (Christern, 2007, P.104).

2.1. Definition of key concepts

2.1.1. Stigma and discrimination

Stigma is “an attribute that is deeply discrediting” and results in the reduction of a person or group “from a whole and usual person to a tainted, discounted one” (Goffman, 1963). Thus, the ultimate effect of stigma, as noted by Goffman, is the reduction of the life chances of the stigmatized through discriminatory actions.

In keeping with Goffman, we do not conceptualize discrimination as separate from stigma, but as the end result of the process of stigma in effect, “enacted” stigma. We define discrimination (or enacted stigma) as the negative acts that result from stigma and that serve to devalue and reduce the life chances of the stigmatized. Goffman defines stigma as a “mark” that links a person to undesirable characteristics (label).

UNAIDS (2003) defines HIV related stigma and discrimination as: “...a’ process of devaluation” of people either living with or associated with HIV and AIDS... Discrimination follows stigma and is the unfair and unjust treatment of an individual based on his or her real or perceived HIV status.

2.1.2 AIDS

AIDS is short for Acquired Immune Deficiency Syndrome. We say that this disease is acquired because it is not a disease that is inherited. It is caused by a virus (The human immunodeficiency virus or HIV) that enters the body from outside. Immunity is the body's natural ability to defend itself against infection and disease. A deficiency is a shortcoming the weakening of the immune system so that it can no longer defend itself against passing infections. A syndrome is a medical term for a collection of specific signs and symptoms that occur together and that are characteristic of a particular condition (Alta Van Dyk, 2007).

2.1.3 Community

The concept of "community" can be defined in various ways:

A community is an entity comprising a rich diversity of groups with shared interests within a specific geographical boundary or neighbourhood that determines this social group (Gott & Warren, 1996, Dreyer, Hattingh & Lock, 1993).

Geographical community: A group of people living in or coming from a defined geographical area, sharing basic values, and organizational structures (Robertson and Minkeler, 1994). Common Identity Community: Groups of people reinforced through their means of livelihood or common practices such as business leaders, truckers, sex workers, men who have sex with men or injecting drugs users (Neill Mc Kee, Jane T. Bertrad, Antje Becker-Benton, 2004).

2.2. Impact of HIV/AIDS related stigma and discrimination

The HIV/AIDS pandemic has evoked a wide range of reactions from individuals, communities, and even nations, from sympathy and caring to silence, denial, fear, anger, and even violence. Stigma is an important factor in the type and magnitude of the reactions to this epidemic (UNAIDS 2002). HIV/AIDS related stigma and discrimination has played an important role in growth and conservation of the epidemic in the world.

At the community level, the fear of stigma can lead to the refusal of voluntary counseling and testing (VCT) for HIV, increased gender-based violence and marginalization of high risk individuals (Heyward et al., 1993). Community members may not try to find VCT because of the panic of discovering that they are HIV positive and fear of the resulting stigma and discrimination that may accompany their HIV/AIDS status.

Thus, HIV/AIDS related stigma and discrimination may have a profound impact on disclosure of HIV status and the subsequent care, support or treatment that HIV positive persons receive (Moneyham et al., 1996; Muyinda et al., 1997; Weiss and Ramakrishna, 2001; Mill, 2003; Carr and Gramling, 2004; Reynolds et al., 2004), and reduced participation in programs to prevent mother- to- child transmission (Nyblade, Lc and M.L, 2000; Bond V. E. Chase and P. Aggleton, 2002).

Stigma is a real barrier to HIV prevention efforts as individuals often do not want to know their status and will avoid testing and further accessing treatment to avoid being seen as an HIV positive person (Daftary et al. 2007; Kalichman and Simbayi 2003; Skinner and Mfecane 2004; Petros et al. 2006). Fear of discrimination also often prevents HIV positive individuals from disclosing their status to their sexual partners (Simbayi et al. 2007).

Studies on AIDS stigma among family and community members have been conducted in Ghana. One study conducted by Mill (2003) explored the experience of HIV-seropositive women felt the need to hide their HIV status due to the perceived shame and disgrace surrounding the HIV infection. HIV counselors also reinforced maintaining secrecy as a strategy to reduce stigma.

A more study examined the effect of HIV stigma on caregivers of PLWHA in Accra. This study observed that caregivers also experienced widespread stigma and discrimination that were exhibited in negative attitudes from

close neighbors, relatives and health care workers (Mwinituo and Mill, 2006).

In addition, qualitative research has revealed that HIV positive individuals prefer to tell others that they have tuberculosis (TB) rather than deal with the stigma of being HIV positive (Daftary et al. 2007).

Despite efforts to reduce AIDS stigma in South Africa, recent studies reveal that: 29 percent of South African respondents would not buy food from a vendor who has HIV (Shisana et al. 2005).

Studies in South Africa have demonstrated the negative impact of AIDS stigma. For example, in Cape Town, 25 percent of HIV positive individuals queried have never spoken with friends or family members about their status and 33 percent of those who have disclosed their HIV status report being treated differently after telling others (Shisana et al. 2005; Simbayi et al. 2007).

2.3. Practicable interventions to mitigate HIV/AIDS related stigma and discrimination.

In Ghana, the stop AIDS, Love Life program created radio and TV spots and materials with an HIV-positive laborer named Douglas Sem, who was the first to speak out about his status in an open way. His openness led to greater political commitment and began to reduce stigma (Tweedie et al., 2002).

Furthermore, in India, the lawyer's collective HIV/AIDS unit works to influence HIV/AIDS legislation, informs PLWHA and organizations addressing HIV/AIDS about appropriate legislation, and directly takes up cases of discrimination in the courts (Lawyers collective HIV/AIDS unit, 2002).

PLWHA involvement in the design and implementation of communication interventions has been shown to reduce PLWHA's own fear of stigmatization

(Horizons, 2002). In Tanzania, a school-based program involving HIV/AIDS education, including small group discussions and role-plays, resulted in significant improvement in attitudes toward PLWHA (Klepp et al., 1997).

When agricultural workers in Zimbabwe learned about HIV/AIDS through peer education and workshops, they became more open in discussions about HIV, indicating reduced stigma (Kerry and Margie, 1996). In India, discussion with staff from three hospitals on the results of baseline research on stigma towards PLWHA led to increased interest and action to reduce stigma, including the development of PLWHA-friendly "gold standards" for hospital programs and staff (Horizons, 2002b).

It is important to mention that; Effective message delivered through mass media channels can support and reinforce interventions conducted at the community level. In India, a documentary film describing the life of PLWHA was produced and broadcast nationally (Venkataraman et al., 1996).

Indeed, PLWHA involvement allows PLWHA to redefine their illness, reconstruct their identities, and develop tools to reduce stigma (Neill McKee et al., 2004). For example, The AIDS Support Organization (TASO) in Uganda. On the other hand, provide counseling and medical care to PLWHA and their families and organizes groups where they can discuss issues they are facing (Kaleeba et al., 1997). Participants report that the program helps them realize that they are not alone. Those PLWHA who are affiliated have high rates of disclosure of their HIV status, indicating reduced stigma. A multi-country study of PLWHA involvement in community-based organizations (in Burkina Faso, India, Ecuador, and Zambia) showed similar results; PLWHA demonstrated reduced fear of stigmatization and feelings of powerlessness (Horizons, 2002a).

According to UNAIDS (1998a), In Uganda, Islamic Medical Association trained over 8,000 religious leaders. An evaluation concluded that the support of official Islam for care of PLWHA is a strong counterweight to

stigmatization. It is important to indicate that; in a project in Thailand, Buddhist monks visited those infected, demonstrated home-based care and educated people on HIV and AIDS. Their activities contributed significantly to reducing stigma in the communities concerned (Busza, 2001; Olkkonen, 2002). Furthermore in Ghana, a multi-media campaign through TV and radio spots linked to community-based activities involves religious leaders as role models for compassionate attitudes towards those infected (Tweedie, 2001).

In short, many researches of HIV/AIDS related stigma and discrimination have been done and the research still going on in order to contribute in the fight against the epidemic that continues to increase the mortality rate in the world.

CHAPTER 3: RESEARCH METHODOLOGY

3.1. Research design

This part of the research will debate the methodology which has been used to accomplish the study. The data obtained from Bukavu community has been collected by using a questionnaire containing quantitative questions. Qualitative questions were used precisely for different organizations which are working in HIV/AIDS field in order to gather information about HIV/AIDS services provided into the community.

Borg and Gall, (1989) define a research design “... as a process of creating an empirical test to support or to refute a knowledge claim”.

Mouton (2001) added by saying: the research design focuses on the end product of the study and the logic of the research. A qualitative approach was chosen because according to Lo Biondo-Wood and Heber (1998) it embraces the wholeness of human, focusing on human experiences in naturalistic settings.

In this specific study, the research design refers to the outline, plan, or strategy specifying the procedure to be used in seeking an answer to the research question. It specifies such things as how to collect and analyze the data. One purpose of the design is to control unwanted variation, which is accomplished by incorporating one or more of the control techniques (Christensen, 2007).

3.2. Sampling method

A sampling theory is in fact the study of the relationship between a population and the samples drawn from it. A sample is the subset of the whole population which is actually investigated by a researcher and whose characteristics will be generated to the entire population (Bless & Higson-Smith: 2000).

A sample size of 150 people was selected from different area in the community to be able to generalize the results to the whole community. The

organisations such as PNMLS (programme National Multi sectoriel de lutte contre le SIDA), Fondation femme Plus, Association de Santé Familiale have been selected for interview. One person was chosen for interview according to his/her manager position in the organization. The age categorizations of the subjects start from 15 and above.

3.3. Data collection method

To gather data in this study, the English questionnaire has been translated into French and administered to the participants. The interviews have been conducted by the researcher to managers of different organizations in order to receive certain information in connection with the services provided to HIV positive and negative in the community. The questions were presented orally and the responses were written down by the researcher.

3.4. Ethical considerations

The study procedures adopted was standardized and made uniform for all respondents. Permission to enter into community and different organization was obtained from the provincial medical inspector. He was informed about the research project his consent was vital to the community and different organizations. The result will be used for research purposes, to develop community interventions and provide guide lines in order to improve the community.

The respondents were informed that the information would be confidential and people who are involved in the research would have access to it. The report findings would be published in such way that the participants would remain anonymous. The respondents were informed that they might choose whether to take part in the study or not. Even if they choose to take part, they may withdraw from the study at any time without consequences of any kind. They may also refuse to answer any questions that they do not want to answer and still remain in the study.

CHAPTER 4: RESULTS

4.1. Biographical details, general characteristics of questionnaire and interview of respondents

The demographical information are based on total of 150 respondents filled the questionnaire. All the respondents live in Bukavu community and were requested to indicate their age and gender.

76 (51%) of the respondents were 15 to 24 years, 39 (26%) were in the middle of the ages 25 and 34 years, 35 (23%) and above

Table 1: age category of respondents (N=150)

Age range	Frequency	Percentage
15-24 years	76	51%
25-34 years	39	26%
35- above years	35	23%
Total	150	100%

79 respondents were males (53%) while 71 respondents were female (47%). The total of the respondents were 150.

Table 2: Gender

Sex	Frequency	Percentage
Male	79	53%
Female	71	47%
Total	150	100%

The majority of the respondent 51% interviewed during the study were between 15-24 years old which correspond to the youth age.

Home Language: Respondents speak a variety of language due to the tribe appurtenance. The community of Bukavu is composed by many tribes and each has its own dialect. To facilitate communication between people, The Swahili as one of the national language spoken in eastern province of DRC, Katanga province and oriental province and French are the two languages

that unite people of different tribe in Bukavu community. In the context of our research, we have judged most useful to use the French language in order to facilitate communication and to avoid confusion and incomprehension between researcher and participants. All respondents (N=150) can speak, understand and write French.

A. Feelings and behaviors of study participants towards PLWHA

1. PLWHA should be isolated to certain village or town.

Of all the respondents, about (69%) indicated that the people living with HIV/AIDS should not be isolated to certain village or town. (19%) of the respondent agreed that PLWHA should be isolated in order to protect those who are not infected. While 8% were not sure about the answers to this question. Few of the respondents about 4% did not answer the question.

One of the respondents who agreed said: *“By isolating PLWHA in their village or town, will be an effective way to fight against the spread of the disease in the community because they will be identified by anyone. Thus, people will avoid them for sex or any other kind of contact which can contribute to the spread of HIV”*. Other studies conducted in Cape Town by (Shisana et al. in 2005), mentioned that: 20% believed that HIV positive children should be isolated to prevent infection.

2. People living with HIV/AIDS must be treated fairly

Of all the respondents (N=150), (73.3%) indicated that PLWHA must be treated fairly. 12 respondents which correspond 8% mentioned that PLWHA must not be treated fairly in the community where they are living. 8% of the respondent did not respond to the answers. 11% of respondents were not sure about the answers to this question.

3. A person who has HIV virus should not be allowed to work to protect the people who not have HIV virus.

Some of the respondents (26%) indicated that it is not safe to work with an infected person. One of the responded said: *“it is very dangerous in case of*

injury especially when we use the same work tools". Others indicated (58%) that an infected person can be allowed to work. 13% were not sure about the question and 3.3% did not answer the question.

4. *It is safe to let my child play toys with children who have*

Respondents were asked whether it is safe to let a child play toys with children who have HIV/AIDS. Of these who responded to this question, 48% responded that they can let their children play toys with HIV/AIDS children. 35% responded that it was not safe to let their children to play toys. Some of the respondents argued that, in case accident of injury their child can be infected. 15% were not sure about the answer to the question. 3% of respondents did not respond.

5. *Children of PLWHA should be treated differently*

A question was asked whether the children of PLWHA should be treated differently. 57% of respondents reported that, children of the infected people should be treated at the same level as others. 31% of the respondents showed a negative feeling against children of PLWHA. 13% of the respondents were not sure about the answer to the question. 0% of no response to the question.

6. *PLWHA and their children should be neglected*

Most of the respondents (75%) mentioned that PLWHA and their children should not be neglected or avoided. (10%) of the respondents agreed the question. One among the (10%) said: "*PLWHA and their children are not people who must live in this world*". While (11%) were not sure about the answer and (3%) did not answer the question.

7. *PLWH and their children have to be physically abused*

Regarding to the PLWHA and their children should be physically abused, (9%) of the respondents agreed the question while the majority of the respondents disagreed (64%). (18%) of respondents were not sure about the answer and (9%) of respondents did not respond to the question.

8. HIV/AIDS women or man must leave his/her partner if his or she is HIV positive

On a question of HIV/AIDS women or man must leave his/her partner if he or she is HIV positive. (48%) of the respondents mentioned they will not leave her or his HIV/AIDS partners. Other respondents (36%) said that they will leave their partners. (15%) mentioned that they were not sure about the answer. About (1%) of the respondents did not respond.

9. Cloths and linen used by HIV positive patients should be

They were asked if the clothes and linen used by the HIV positive patients of or burned. The majority of responded about 73% disagreed while 16% agreed and 11% were not sure about the answer and 1% means one person of the respondents did not respond.

10. PLWHA should be kept at a distance from other patients.

Respondents were asked whether PLWHA should be kept at a distance from other patients. Of the 150 people who responded to this question, 49% agreed that PLWHA must be separated from other patients. 42% of the respondents disagreed. 9% of the respondents were not sure about the answer to this question while 1 person among 150 respondents did not respond.

11. If you knew a shopkeeper had HIV/AIDS, would you buy vegetable from him?

A question related to a shopkeeper who is AIDS patient. The majority of the respondents (89%) have responded positively by saying "Yes" which means they can buy bread from him/her. (11%) responded by "No" Which means they cannot buy from/her. One of the responded argued by saying that: "If I buy bread from him/her I will not have appetite to eat the bread I can even vomit." The same question has been asked in the research conducted by Shisana et al. (2005) in South Africa mentioned in our literature review. The studies revealed that 29% of South African respondents would not buy food from a vendor who has HIV.

12..Would you provide care and support for an HIV/AIDS person?

The Percentage of respondents who mentioned that they can provide care and support for an HIV/AIDs person was high about (95%). Followed by (3%) of respondents mentioned that they cannot provide care and support, the reasons were not explained. Others about (3%) did not want to respond the question.

13.Would you touch or hug a person who has AIDs

The percentage of respondents who can touch even hug an AIDS person was also high (79%) than those who mentioned that they cannot touch or hug an AIDs person (21%). The respondents were asked to justify their answers if they have responded by “NO”. *One of the respondents said that” these people must not live in this world”. The second one said:” AIDS patient does not present a good appearance; he must live away from other people as I have said to the first question”. The third respondent argued that: “AIDS patient can have wound on his/her body because of that, I must protect myself by not touching or hugging him/her.”*

14. Imagine you find out that one of your friends is infected, would you still be friends with him/her

Respondents were asked if they can still be friend to one who is infected by HIV virus. The percentage of respondents who declared “yes” was higher about (89%) than those who have mentioned “No” about (21%). And (0%) indicated that no response to the question.

15. If a teacher has HIV virus but is not sick, should he or she allowed continuing teaching in school?

In addition, the majority of the respondents around (91%) said “Yes” that, an HIV teacher can be allowed continuing teaching in school. One of the respondents argued: *“If a teacher continues to do his job, he must stop doing sex “.* (7%) of the respondents mentioned that HIV positive teacher cannot

continue to work and (1%) of the respondents did not respond to the question.

16.If a student has HIV/AIDS, should he or she allow continuing attending school?

Most of the respondents (97%) indicated that a student can has HIV/AIDs and still continue to attend class while (3%) indicated that an HIV/AIDS student cannot attend class. (0%) showed that no response to the question.

17.Can you rent your house to a PLWHA? If no why

A large number of respondents (88%) reported that they can rent their house to people living with HIV/AIDS. Ten percent (10%) of the respondents by saying “NO” they cannot rent their house to PLWHA. If the answer was “NO”, the respondents were asking to explain. One respondent said” *If I rent my property to HIV/AIDs patient, in the future when he/she will be too ill with AIDs infection, then the patient will not be able to pay rent*”. The rest of the respondents did not justify their “No” 2% of the respondents did not respond to the question.

18.If you find your co-worker has HIV/ AIDS would you willing to work with him?

It can also be noted that several respondents about (73%) they will work with a co-worker who has HIV/AIDS. Following by 21% of respondents who did not answer to the question While (7%) of the respondents did not agree to work with PLWHA.

19.Would you willing to share a meal with an HIV/AIDs person?

The percentage of respondents (91%) who mentioned that they can share a meal with people living with HIV/AIDs was higher than the percentage of respondents (6%) who responded they cannot share the meal with HIV/AIDS people. Only (3%) of the respondents did not respond.

B. Questions for disclosure*20. PLWHA should tell others they are HIV positive.*

In this section, respondents were asked if PLWHA should tell others they are HIV positive. In the response to the question, about 59% of the respondents agreed while 20% disagreed. 15% of the respondents were not sure about the answers to this question and only 7% did not give a response to this question.

21. Should it be kept a secret if family member is HIV positive?

A question that followed was for the respondents to indicate that if should it be kept a secret if family member is HIV positive? 53% of the respondents said they would keep secret if family member is HIV positive. On the other hand, 42% of the respondents reported that they will not keep secret if a family member is HIV positive. 5% did not give the response to this question.

22. In your community, what are the primary way people know if someone has HIV?

Statement	frequency	percentage
1.The infected person discloses his/her status	26	17%
2.From the general rumors/gossips	30	20%
3.from the HIV-positive's family	4	3%
4.form the HIV-positive's employer	0	0%
5. from the HIV-positive's friends/neighbors.	4	3%
6. from the health center/health care worker where the person got tested	64	42%
7.the person looks ill and has lost a lot of weight	8	5%
8.other (specify)	8	5%
9. No response	7	5%
Total	150	100%

The respondent were presented with different set of responses in order to indicate the way they know that someone has HIV in the community. Of the

150 who responded to this question, the high percentage was (42%) reported that they knew from the health center/health care worker where the person got tested. 20% of respondents have known from the general rumors and gossips. 17% from the infected person who disclosed his/her status and 5% indicated that the person looks ill and has lost a lot of weight. Other 5% of respondents gave others different answers.

Only two respondents have specified their answers. One said, I knew that someone as HIV from the brothers of my church and the second respondent through the signs which appeared on his body. Few of the respondents (3%) indicated from the HIV-positive's family and 3% identified from HIV-positive's friends/neighbors. 0% of the respondents indicated from the HIV-positive's employer. 5% of the respondents did not indicate mentioned the response to this question.

C. Interview questions for organizations

During the era of HIV/AIDS pandemic in Bukavu community, most international agencies, national, government, on-governmental organization stated the initiatives in care and supports services, in order to minimize the rate of infection as well as fight against HIV/AIDS related stigma and discrimination .

For this reason, the researcher found that it was useful to be in contact through interview with managers of some organizations in order to know the different services that are provided in the community which can facilitate the tracks of solutions to the problems.

Of these organizations, the researcher had selecte we can mention: PNMLS (Programme National Multisectorial de lutte contre le sida) which means in English: (National Multi-sectorial fight against AIDS), ASF (Association de Santé Familiale) means in English: (Association of Family Health), Fondation femme Plus, UCOP (Union Congolaise des personnes vivant avec VIH/SIDA) means in English: Congolese Union of people living with HIV/AIDS.

1. Le PNMLS (National Multisectorial fight against AIDS)

The government's National Multi-sectorial Programme for the fight against HIV/AIDS, known by its French abbreviation PNMLS.

PNMLS is the agency coordinating the fight against HIV/AIDS in the Democratic Republic of the Congo under the overall authority of the president of the republic. To meet the challenges of the fight against AIDS on all sectors of national life, PNMLS has a mission to mobilize and to coordinate all organizations of the fight against AIDS in the DRC.

Its objective is to contribute to national reconstruction and development of the country by slowing the spread of the epidemic of HIV/AIDS and its impact on individuals, families, communities and productive sectors.

During the interview with secretary of the coordinator, the researcher wanted to know if the organization provides HIV/AIDS education to the community. The answer was "Yes" *accepts life skills*. The second question have been asked whether the organization provide the community with information on where the people can receive HIV counselling and testing. The answer was "yes" *we do the campaigns of awareness in the community, and also through the media such as: radio and billboards informing the community about VCT and newspapers*.

The researcher wanted to know if the organization has sites peer education the answer was "yes", *we do have different sites*.

Other question, does your organization have peer education which can get involved in HIV/AIDS related stigma and discrimination? The answer was "Yes" *we always talk to our peers about that*.

The researcher needed also to know whether the organization has the necessary manuals for the education of peers. The answer was "yes" *but not enough*.

A question was asked if the organization has HIV and STI materials such as posters and pamphlets available for the community. The answer was “No” *we do not use posters and pamphlets.*

Another question was asked if the organization has a working video player or projector, television. *The respondent replayed that; within our organization, we have a mobile video service which serving our community as well as the film.* Furthermore, the researcher wanted to know whether the organization has special support programs for PLWHA regarding stigma and discrimination in the community. The respondent answered that; in the fight against HIV/AIDS related stigma and discrimination in the community, our organization (PNMLS) works with code of law no: 08/011 of 14 July 2008 on the protection of the rights of people infected and affected with HIV/AIDS. The articles were written in French translated into English by the researcher.

Article 10 it says: “is banned in public and private health institutions all forms of stigma or discrimination against a patient because of his HIV status known or suspected by his/her spouse or his /her relatives”.

Article 20 it says: “It prohibited in the workplace or training any stigma or discrimination against a person because of his or status known or suspected of his/her spouse or his/her relatives”. *After the respondent continued to say that, the organization collaborates with an association of lawyers that is called “Groupe Calin” in order to raise awareness of the law relating to stigma and discrimination in the community.* Referring to the literature review, in India, the lawyer’s collective HIV/AIDS unit works to influence HIV/AIDS legislation, informs PLWHA and organizations addressing HIV/AIDS about appropriate legislation, and directly takes up cases of discrimination in the courts (Lawyers collective HIV/AIDS unit, 2002).

Other strategies we have implemented as part of the fight against HIV/AIDS related stigma and discrimination. *We use people living with HIV/AIDS who have disclosed their HIV status in order to educate the community about HIV/AIDS. Referring to the literature review, PLWHA involvement allows PLWHA to redefine their illness, reconstruct their identities, and develop tools to reduce stigma (Neill Mc Kee et al., 2004. We also use Medias such as: government agency (Congolese national radio and television), press agency" Kivu Safari", religious leaders, political leaders, youth, old people, and billboard. Supplementary we fund small business projects such as: mills, bakeries and brickyard where PLWHA work. Those different activities play an important role to deal with stigma and discrimination in our community.*

The researcher needed also to know if there is any HIV/AIDS committee or clubs in the community. The respondent answered by "No".

The researcher desired to know whether some people have undergone HIV training. The answer was "Yes they have done a workshops training"

1. Association de Santé Familiale (ASF)

Association de Santé Familiale in English means Association of Family Health, known by its French acronym "ASF". ASF, a national NGO allied to Population services International (PSI) in short. The NGO ASF works with HIV/AIDS met every month, under the chairmanship of PNMLS.

The researcher was in face to face interview with the manager of the organization, he was asked if the organization provides HIV/AIDS education if yes does the curriculum cover: peer education program, care of PLWHA, counselling, testing program and life skills. The answers was "Yes" he clarified by saying: *We have the manuals for this purpose, which we use to teach the peers. We target commercial sex workers, pupils especially those who are in grade eleven and twelve, soldiers, truck drivers, youth as well as people belonging to various religious. A small group in every target group was trained to inform their peers about HIV/AIDS.*

The researcher wanted to know if the organization provides the community with information on where people can receive counselling. *The respondent mentioned that; in our VCT awareness campaign, we target the very popular areas such as: Quartier essence, Quartier Nyamugo, Beach Muhanzi by playing music, we make comedies, we set up stands then we encourage people to come for VCT. In the ground, people who are interested we give them a reference cards to visit a facility for testing and counselling. At back side of the cards there is a list of medical facilities and VCT centres, where possible patients can be served for free of charge.*

The respondent was asked if the organization has any HIV and STI materials such as posters and pamphlets available for the community. The answer was "No" *we do not have those kind of material.*

In the following questions the researcher needed to know if the organization has a working video player, television and a support program for PLWHA regarding stigma and discrimination. *The respondent indicated that, there is mobile video service and we also use media such: government agency (Congolese national radio and television), private media agency is called "Radio maendeleo".* The respondent was asked if the organization has clubs or HIV committee that address or focused on HIV/AIDs. The answer was "Yes" *the respondent mentioned that the organization works with pupils and some students.*

Finally, the respondent was asked if some people have undergone training in HIV in your organization. The Respondent said that: *"our field team has been trained"*

1. Union congolaise des personnes vivant avec VIH/SIDA (UCOP)

UCOP is an acronym of Congolese union of people living with HIV/AIDS. UCOP is a local NGOS that deals with the management of people living with HIV/AIDs, promote a positive prevention which include: the use of condom, MTCT, orientation of people to VCT centres, how people can live with PLWHA and protection against sexually transmitted diseases as well as HIV

infection. In our duty, we also deal with medical care as well as psycho social support to PLWHA.

The researcher asked: does your organization provide HIV/AIDS education? If yes does the curriculum cover: Peer education program, care for PLWH, counselling testing program and Life skills. *The respondent mentioned that we educate people in general; few people came for VCT due to the stigma and discrimination. Other issue is that our organization does not have all the necessary tools for VCT and also we do not educate people about life skills.*

The respondent was asked whether the organization provide the community with information on where people can receive HIV counselling. The respondent answered by” No” *by seeing we do not do that.*

The researcher desired to know is there is manuals available for peer education. The answer was: *“We do not have any manual for Peer education”*

The following question was: do you have HIV and STI materials such as posters, pamphlets? The answer was: *“we do not have those kinds of materials”*. Are there video player, projector, working television and films on HIV/AIDS related to stigma and discrimination? The answer was: *“we do have video player but we do not have films regarding HIV/AIDs in general”*

The respondent was asked if the organization have a special support program for PLWHA regarding stigma and discrimination. *The answer was “yes”. He said the organization use the private media agency which we call “radio maendeleo”.* The researcher wanted to know if the organization has clubs that address or focused on HIV/AIDS related to stigma and discrimination. The answer was” Yes”; *we do have nine clubs in different areas in the Bukavu community such as: Mufariji, Abamuli, grace, Gast, Twikile, AleF+, Mchs, ADECOP and Kyobo.*

The responded continued to say that, these young people who work in these different clubs do not work with motivation due to the lack of payment.

The research wanted to know if some people in your organization have undergone training in HIV/AIDS. *The participant answered that thirty people have been trained*

Fondation femme Plus/ Sud Kivu

Fondation femme plus is a local non-governmental organisation which means in English women foundation. It is one among the local NGOs which are interested by the HIV problems on the territory of the Democratic Republic of the Congo.

In the field of HIV/AIDs women foundation as a local non-governmental organization has following HIV/AIDS activities:

- Psycho social, spiritual and moral assistance
- Promoting a positive living and positive prevention
- Popularization of the law on protection of PLWHA
- Testimony of PLWHA
- Holding meeting with PLWHA
- Care and treatment for PLWHA and Mobile VCT

The respondent was asked if their organization provide HIV/AIDS education to the community. The respondent said that: *“we do educate people about HIV/AIDs especially when we are in our mobile VCT campaign. Regarding peer education, we target the truck drivers, motorcyclists, soldiers and merchants but we do not educate people about life skills”.*

Does your organization provide the community with information on where people receive counselling? The respondent said *“yes “we do educate people during our VCT campaign and also have VCT centre.*

The research wanted to know if the organization has on site peer education that can get involved in HIV/AIDS related stigma and discrimination. The respondent answered by” *Yes” we educate our peers about HIV/AIDS related stigma and discrimination.*

The researcher desired to know is there is manuals available for peer education. The respondent said: *“not necessarily it like we do not have manuals”*

The researcher wanted also to know if the organization has HIV and STI materials such as posters and pamphlets available for the community. The participant response was” No” *we do not have*

The following question was: do you have a working video player, television? The respondent said that:” *We do have equipment but we do not have film”*

The respondent was asked if their organization has special support program regarding stigmatization. The respondent said:” *the organization does not have that special program”*

Does your organization have a clubs or committee in the community that address or focused on HIV/AIDS related stigma and discrimination? The respondent answered by saying” No”

Are there people in your organization that have undergone training in HIV? The respondent said: *“Yes the people was trained”*

4.2. Findings

Concerning all the questions associated to the feelings and behaviours of study participants towards PLWHA, the researcher have found that a significant majority of the participants in the research have shown a largely positive feelings and behaviours towards people living with HIV/AIDs in the community.

The finding of the study revealed that the important majority (69%) of the respondents disagreed the isolation of PLWHA, (73%) of respondent agreed that PLWHA must be treated fairly. A large majority of the respondents (58%) disagreed that a person who has HIV should not allow to work, to

protect the people who do not have HIV virus. Regarding child who plays toys with children who have HIV/AIDS, a limited majority of respondent (48%) agreed. 57% of respondents did not agreed that children of PLWHA should be treated differently.

A significant majority of the respondents (75%) disagreed that PLWHA and their children should be neglected. A considerable majority of the respondents (64%) disagreed that PLWHA and their children should be physically abused. (48%) of respondent disagreed about the leaving of the partner who is HIV positive. A simple majority of the respondents (49%) PLWHA should not be kept at a distance from other patients, and a significant majority of the respondents (73%) disagreed that the cloths and linen used by HIV/AIDS patients should be disposed of or burned.

In addition, an overwhelming majority of respondents mentioned (89%) that, they can buy vegetables from HIV/AIDS shopkeeper, (95%) of the participant said they can provide care and support to PLWHA. The question regarding touching and hugging an AIDs person, a long majority of the respondents (79%) have indicated that they can hug and touch an AIDS person while a high percentage (89%) of respondent have showed a positive feeling to HIV positive friend.

The finding of the study revealed that (91%) of the respondents said that an HIV positive teacher can still continue to work, (97%) of participants indicated that HIV student can still continue to attend class. The findings revealed that (88%) of the respondents accepted to rent their house to PLWHA, (73%) of respondents agreed that they can work with their co-worker who has HIV/AIDS.

Many of these respondents (91%) accepted to share meal with HIV positive person. On the other hand, regarding the questions related to disclosure in several cases, PLWHA perceived and experienced further discrimination when HIV status is revealed. However, (59%) of respondents agreed that

PLWHA should tell others about their HIV status. The study also found that 53% of respondents agreed that it should be kept a secret if family member is HIV positive.

It was important to note that, the researcher have discovered through data analysis that there is three main ways to know if someone is HIV positive in the community of Bukavu. Firstly, a limited majority of respondents (42%) has revealed that the health centres/health care workers told them about the HIV status of some. Secondly, the rumours/gossips are the second way to know about HIV status of someone in the community. (20%) of the participants mentioned they knew about someone's HIV status through rumours/gossips. Thirdly, (17%) of respondents have known whether someone is HIV positive through an HIV infected who disclosed her/his status.

A very few of respondents (21%) mentioned others different ways that they know that someone his/her HIV positive such as: from the HIV positive's family, from the HIV positive's friends/neighbours, the person looks ill and has lost a lot of weight and the church brothers disclose the HIV status of church member.

In the context of organizations, the research findings reveal that all the four organizations do not provide life skill education to the community. The study also showed that all the organizations selected provided information about VCT as well as peer education. Only two organizations have manuals available for peer education training but not sufficient. The study found that the organizations do not use posters and pamphlets for the community.

Regarding the questions related to materials such as: video players, television projector screen and films all of them indicated that they have Video players but two mentioned that they do not have films. Concerning the special support programs for PLWHA, the researcher found that one organization does not have support program. The findings revealed that Two

organizations have HIV clubs among the four selected. The findings also reveal that only two organizations have HIV/AIDS committee. Finally the findings mentioned that the people of the four organizations have been trained.

CHAPTER: 5 CONCLUSION, RECOMMENDATIONS AND REFERENCES

5.1 Conclusion

The conclusion of this research is drawn from the findings. The study concluded that the respondents indicated a good feelings and behaviours to PLWHA. Furthermore, the result has indicated that health care worker, counsellors, did not respect the principle of confidentiality of the people who have been tested. No respect of the confidentiality may hinder community from using services as well as stigmatize the PLWHA. In the same logic, the result indicated (59%) of respondents agreed that PLWHA should tell other people that they are HIV positive in order to protect those who are not infected. This can be one of the factors that contribute to the stigma about discrimination in the community.

Moreover, in the qualitative analysis, the results showed that the support services provided by HIV/AIDS organizations were very limited in the community. Ultimately a lot of HIV/AIDS effort is needed to be done in Democratic Republic of the Congo in general and Bukavu community in particular. It is time for everyone to be aware and get involved in the fight. Political leaders, religious leaders, private and public institution, local and international NGOs, all are concerned to work together in order to build healthier families, communities and nations.

5.2. Recommendations

According to Neill M. et Al (2004), people living with HIV/AIDS need more than medical support; they need emotional and spiritual support and they need to live in caring communities. This will slow the spread of HIV because people would not be so likely to hide their status if they could expect more compassion. Information and experience that we had in writing this article, the following suggestions have been made on the basis of the findings of the research.

- The findings of the research indicated that, a large majority of the respondents had a positive feelings and behaviour toward people living with HIV/AIDS. In this context, the study recommends all organizations involved in HIV/AIDS activities to promote positive feeling and behaviour to PLWHA.
- The study recommends training for health providers and counsellors. The training should include the right of PLWHA, counselling skills and confidentiality rules.
- The study recommends also the upgrading of communication strategy plan by including print materials, such as pamphlets, booklets, posters, stickers, and T-shirts support.
- Life skills programmes should be part of HIV/AIDS education. Findings revealed that there is lack of life skills training as well as manuals for peer education training.
- Educating peoples in the community in order to make optimal use of the services.
- Fight against rumours/gossips due to HIV/AIDS status by improving the quality of counselling and establish HIV/AIDS committee and clubs in the community.
- Stakeholders need to promote the existing Voluntary Counselling and testing
- Finally, there is an urgent need of politic solution in order to stop the continuity of rape, and other kind of insecurities that hamper people to get access to the HIV/AIDS services in the rural areas which surrounding Bukavu community.

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Appendix A



UNIVERSITEIT • STELLENBOSCH • UNIVERSITY
jou kennisvennoot • your knowledge partner

STELLENBOSCH UNIVERSITY CONSENT TO PARTICIPATE IN RESEARCH

[Insert title of the study.] [If the study involves using different consent forms for different populations, identify the population group as the subtitle of the study.] HIV/AIDS related stigma and discrimination in the community. Bukavu community in the Democratic Republic of Congo. The study will not use any consent forms for different population.

You are asked to participate in a research study conducted by [insert names and degrees of all investigators], from the [insert department affiliation] at Stellenbosch University. [If student, indicate that results will be contributed to research paper, thesis or dissertation.] You were selected as a possible participant in this study because [explain succinctly and simply why the prospective subject is eligible to **participate**].

The study is conducted by Barthelemy WENGA MULINDWA as part of a fulfillment of a dissertation as an MPhil student in HIV/AIDS management at the University of Stellenbosch. This subject is eligible to participate because I realized in my community it is going to be difficult to undergo HIV/AIDS prevention project if there is no resolution of stigma and discrimination in the community.

1. PURPOSE OF THE STUDY

[State what the study is designed to assess or establish]

The purpose this study is to identify possible factors which are contributing to HIV/AIDS related stigma and discrimination in my community.

2. PROCEDURES

If you volunteer to participate in this study, we would ask you to do the following things:

[Describe the procedures chronologically using simple language, short sentences and short paragraphs. The use of subheadings helps to organize this section and increases readability.

Medical and scientific terms should be defined and explained. Identify any procedures that are experimental.] Questionnaire is procedure experimental which will be used. The questions will focus on testing the attitude or behaviors of participants towards people living with HIV/AIDS, question about disclosure and question and question regarding HIV prevention.

[Specify the subject's assignment to study groups, length of time for participation in each procedure, the total length of time for participation, frequency of procedures, location of the procedures to be done, etc.] Four days

3. POTENTIAL RISKS AND DISCOMFORTS

[Describe any reasonable foreseeable risks, discomforts, inconveniences, and how these will be managed.] The study asks about attitude, feelings that can cause psychological risk and the time which will spend answering questions.

[If there are significant physical or psychological risks to participation that might cause the researcher to terminate the study, please describe them.]

4. POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY

[Describe benefits to subjects expected from the research. If the subject will not benefit from participation, clearly state this fact.]

[State the potential benefits, if any, to science or society expected from the research.]

The result of this particular project will be an instruction in the community and organizations engaged in HIV prevention so that they can learn and improve their quality of HIV/AIDS services and build HIV/AIDS awareness among HIV negative as well as positive people.

5. PAYMENT FOR PARTICIPATION

[State whether the subject will receive payment. If not, state so. If subject will receive payment, describe remuneration amount, when payment is scheduled, and proration schedule should the subject decide to withdraw or is withdrawn by the investigator.] No payment will take part in this research

6. CONFIDENTIALITY

Any information that is obtained in connection with this study and that can be identified with you will remain confidential and will be disclosed only with your permission or as required by law. Confidentiality will be maintained by means of [describe coding procedures and plans to safeguard data, including where data will be kept, who will have access to it, etc.]. [If information will be released to any other party for any reason, state the person/agency to which the information will be furnished, the nature of the information, and the purpose of the disclosure.] [If activities are to be audio- or videotaped, describe the subject's right to review/edit the tapes, which will have access, if they will be used for educational purpose, and when they will be erased.] [If researcher is planning to publish results of study, describe how confidentiality will be maintained in publication]

The study procedures adopted will be standardized and made uniform for all respondents. Permission to enter into community and different organization

will be obtained from the authorities of the local government. They will be informed about the project and their consent will be important to the community and different organizations. The result will be used for research purposes, to develop community interventions and provide guide lines in order to improve their interventions in the community.

Confidentiality will be observed and unauthorized persons will not have access to the data collected. Each subject will be assigned a study identification number, and these subject identifiers will not be released outside the research group. Codes will be used and no identification will be made for the responders. Data will only be accessed by the research group. Respondents will be informed that their data will be used anonymously and that the aim of the study is to understand better the problems and how HIV/AIDS related stigma de mitigate.

7. PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and still remain in the study. The investigator may withdraw you from this research if circumstances arise which warrant doing so. [If appropriate, describe the anticipated circumstances under which the subject's participation may be terminated by the investigator without regard to the subject's consent.]

Participating in this study is voluntarily. You can withdraw in the study anytime, for any reason if you decide. Your decision will not undermine or affect our project.

8. IDENTIFICATION OF INVESTIGATORS

If you have any questions or concerns about the research, please feel free to contact [identify research personnel: Principal Investigator, Supervisor, and Co-Investigator. Include day phone numbers and addresses for all listed

individuals. For greater than minimal risk studies, include night/emergency phone numbers.]

9. RIGHTS OF RESEARCH SUBJECTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. If you have questions regarding your rights as a research subject, contact Ms Maléne Touché [mfouche@sun.ac.za; 021 808 4622] at the Division for Research Development.

SIGNATURE OF RESEARCH SUBJECT OR LEGAL REPRESENTATIVE

The information above was described to [me/the subject/the participant] by [name of relevant person] in [Afrikaans/English/Xhosa/other] and [I am/the subject is/the participant is] in command of this language or it was satisfactorily translated to [me/him/her]. [I/the participant/the subject] were given the opportunity to ask questions and these questions were answered to [my/his/her] satisfaction.

[I hereby consent voluntarily to participate in this study/I hereby consent that the subject/participant may participate in this study.] I have been given a copy of this form.

Name of Subject/Participant

Name of Legal Representative (if applicable)

Signature of Subject/Participant or Legal Representative Date

SIGNATURE OF INVESTIGATOR

I declare that I explained the information given in this document to _____ [name of the subject/participant] and/or [his/her] representative _____ [name of the representative]. [He/she]

was encouraged and given ample time to ask me any questions. This conversation was conducted in [Afrikaans/*English/*Xhosa/*other] and [no translator was used/this conversation was translated into _____ by _____].

Appendix B

QUESTIONNAIRE

Name:

Surname:

Home address:

Contact number:

Gender:

Age:

This interview is being conducted to get your input regarding my research topic. If you agree we can proceed.

Please mark your response with X in the appropriate place

Section1: Community questionnaire

A. Feelings and behaviors of study participants towards people living with HIV/AIDS (PLWHA)

1. PLWHA should be isolated to certain village or town. Agree/ Disagree/ Not sure/no response
2. PLWHA should tell others they are HIV positive. Agree/Disagree/ Not sure/no response
3. PLWHA must be treated fairly. Agree/disagree/ Not sure/no response
4. A person who has HIV should not be allowed to work to protect the people who do not have HIV virus. Agree/ Disagree/ Not sure/no response
5. It is safe to let my child play toys with children who have HIV/AIDS. Agree/ Disagree/Not sure/no response
6. Children of PLWHA should be treated differently. Agree/Disagree/ Not sure/no response
7. PLWHA and/or their children should be neglected/ avoided. Agree/ Disagree/ Not sure/no response
8. PLWHA and their children be physically abused. Agree/ Disagree/Not sure/no response
9. HIV/AIDs patient should be kept at a distance from other patients. Agree/ disagree/not sure/no response.

10. Closes and linen used by HIV patients should be disposed of or burned. Agree/disagree/not sure/no response
11. If you knew a shopkeeper had HIV/AIDS, would you buy vegetable from him/her?
Yes/ No.
12. Would you provide care support for an HIV/AIDS positive person?
Yes/No
13. Would you touch or hug a person who has AIDS? Yes/ if No why?
14. Imagine you find out that one of your friend are HIV infected. Would you still be friends with him/her? Yes/No
15. If a teacher has HIV virus but is not sick, should he or she be allowed to continue teaching in school? Yes/ No
16. If a student has HIV/AIDS, should he or she allow continuing attending school? Yes/ No
17. Would you willing to share a meal with an HIV-positive person?
Explained your answer
18. Can you rent your house to a PLWHA? If NO explain your answer
19. I f you find that your co-worker has HIV/AIDS would you willing to work with him? Explain your answer.

B. Question for disclosure

20. Should it be kept a secret if family member is HIV positive?
21. In your community, what are the primary way people know if someone has HIV?
 1. The infected person discloses his/her status.
 2. From the general rumors/gossip.
 3. From the HIV-positive's family
 4. From the HIV-positive's employer
 5. From the HIV-positive's friends/neighbors.
 6. From the health center/health care worker where the person got tested.
 7. The person looks ill and has lost a lot of weight
 8. Other (specify)

22. Is there anyone you know in the health facility who has HIV, but has not yet shown signs and symptoms of AIDs? How did you know that he/she has HIV infection?

1. The infected person told me her/himself.
2. Family member of infected person told me.
3. Community member told me
4. General rumors/gossip
5. From a health care provider where the person tested.
6. Read from his/her hospital file
7. Other (specify)

Section 2: Organizations questionnaire

1. Does your organization provide HIV/AIDS education? Yes/NO

If yes does the curriculum cover:

- Peer education program. Yes/NO
- Care for people living with HIV/AIDS. Yes/NO
- Counseling and testing program. Yes/NO
- Life skills (communication, abstinence, relationships, drug and alcohol abuse...) Yes/NO

2. Does your organization provide the community with information on where people can receive HIV counseling and antibody testing? Yes/No

If yes do the people come for VCT? If No what can be the reason?

3. Does your organization have on site peer education that can get involved in HIV/AIDS related stigma and discrimination? Yes/No

4. Are peer educator manuals available?

5. Do you have any HIV and STI materials such as posters and pamphlets available for the community Yes/No

6. Do you have a working video player or projector? Yes/No

7. Do you have a working television or projector screen? Yes/No

8. Do you have videos or films on HIV/AIDS related stigma/discrimination? Yes/No

9. Does your organization have special support programs for PLWHA regarding stigmatization? Yes/No

10. If yes how many PLWHA benefit from this programs? please enter the number
11. Does your organization have clubs that address or focused on HIV/AIDS related stigma/discrimination? Yes/No
12. Does your organization have other HIV related activities in the community? Yes/No if yes specify.
13. Does your organization have a HIV/AIDS committee in the community? Yes/No
14. Are there people in your organization that have undergone training in HIV? Yes/No if Yes, enter the number
15. What problems do you find when you provide your service in the community?

Appendix C



REPUBLIQUE DEMOCRATIQUE DU CONGO

MINISTERE DE LA SANTE PUBLIQUE

PROVINCE DU SUD KIVU

INSPECTION PROVINCIALE DE LA SANTE
B.P. 1899 BUKAVU



Bukavu, le 20 / 09 / 2010

N° 251/...../B.MIP/SK/2010

Transmis copie pour information à :

- ✓ - Mr Barthélemy Wenga Mulindwa
Etudiant en Master à l'Université de Stellendusch
South Africa

Objet : Recommandation

***A Messieurs les Responsables des Services
Etatiques, ONG Internationales et locales
de Santé de la Province du Sud-Kivu
(Tous)***

Messieurs les Responsables,

La lutte contre le VIH/SIDA est un domaine multidimensionnel et disciplinaire qui interpelle tout le monde en cette période où la maladie a un caractère pandémique.

Notre province qui a connu des périodes de turbulence dues aux multiples guerres est une province à risque et mérite une attention tout à fait particulière ; c'est dans ce cadre que je vous recommande Monsieur Barthélemy Wenga Mulindwa, étudiant en Master pour la récolte des données liées à la maladie afin de lui permettre d'envisager les possibilités de contribuer à cette lutte.

Je vous demande de bien l'accueillir et lui disponibiliser toutes les informations nécessaires à ses préoccupations.

Dans l'espoir que ma requête rencontrera votre assentiment, je vous prie d'agréer, Messieurs les Responsables, l'expression de ma franche collaboration.



Le Médecin Inspecteur Provincial

: Manu BURHOLE MASUMBUKO :=